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COPING WITH A CHILDHOOD CANCER DIAGNOSIS



A childhood cancer diagnosis touches everyone involved—the child and his or her parents, siblings, other family members and friends. In this section, you will find coping strategies for all those who may be affected by the diagnosis.

Your Child. After a cancer diagnosis, your child will need to cope with many changes. Challenges include being in an unfamiliar environment, meeting and trusting healthcare professionals and undergoing procedures that may be uncomfortable. Your child may feel a loss of control over his or her world. The extent of your child's distress depends on your child's age and personality. To help your child to adjust and to accept these changes, try to maintain a supportive yet matter-of-fact attitude.

Behavior Changes. Children who have serious illnesses are likely to show changes in behavior. Recognize that your child will continue to grow and develop throughout the course of cancer treatment. When your child is coping with the cancer diagnosis, the illness and its treatment, you may notice some of the following behaviors:

- Children who tended to be moody and have tantrums prior to their illness are likely to have an increase in these behaviors.
- Children who are particularly prone to worrying may need extra reassurance.
- Children who tended to be withdrawn prior to their illness may become more withdrawn.
- Some children may regress to an earlier stage of development. For example, your child may want to sleep with a stuffed animal that he or she has not paid attention to for some time.
- Children may have difficulty sleeping as a result of anxiety and fear of medical procedures or their illness.
- Some children may want to have closer contact with a parent in a way they have not shown for some time.
- Some older children may seek privacy and have difficulty dealing with parental concerns and monitoring related to their illness.
- Some children may seem to mature emotionally and/or intellectually sooner than their peers. They may ask a lot of questions and want to be very involved with their own care and medical decisions.

Ways You Can Help Your Child to Cope. It will help your child to cope with his or her illness if you

- Provide structure. Children crave structure. It makes their environment feel more predictable and, thus, more secure. It can also increase the sense that their parents and people they trust are in control of the situation. Make their daily lives consistent whenever possible. For example, plan a regular routine that you will follow during your time together in the hospital or clinic.
- Allow your child to make choices when possible (for example, let him or her choose which movie to watch, or what snack to eat). This can help your child with his or her feelings of loss of control.
- Acknowledge and praise your child when he or she is doing difficult things. Praise is the best way to reinforce your child's good behavior.
- Use touch to comfort infants, toddlers and older children. Hold or rock your child. Even if your child does not understand your words, the sound and tone of your voice can still be comforting, too.
- Use the same consequences for bad or inappropriate behavior as you did before your child was diagnosed with cancer. Consistency will maintain structure and normalcy.

- Show that you respect your child's feelings of anger, worry, sadness or fear. Give your child appropriate outlets for expressing these feelings, such as drawing or keeping a journal.
- Keep your child busy with activities during treatment to take his or her mind off difficult and unpleasant experiences.
- Help your child to stay connected with friends from home and school with phone calls, video chats, emails, texts or visits, if possible.
- Look for support groups for children with cancer in your area or online. Talking to other children who are going through a similar experience can be very helpful for your child.
- Ask for professional assistance from the healthcare team for your child if he or she is having an especially difficult time adjusting to the cancer diagnosis and its treatment.



LLS Pediatric Monthly and Weekly Calendar. Your entire family can use this calendar to keep up with each other's busy schedules. The calendar is a magnetic dry erase board that features space for monthly and weekly events and extra space for notes. The calendar includes magnets for you and your children to mark

- General activities such as school, sports events and family time
- Treatment-related appointments, such as treatment days and hospital stays
- Feelings and moods related to the upcoming events



For more information about this free resource, contact an LLS Information Specialist at **(800) 955-4572.**

For assistance finding a support group, ask members of the healthcare team about local support groups or contact an LLS Information Specialist at **(800) 955-4572.**

School-aged Children. Your child may be unable to attend school for some period of time following a blood cancer diagnosis. School is a major part of a child's life, and the loss of social outlets, connection to friends and play activities can be upsetting for many children. Keep lines of communication open between your child's school, the hospital and home. For example, classmates can maintain ongoing contact with your child during his or her absence by telephone, email, texts or video chat. Ask your child's teacher(s) to make a personal phone call, send a note or visit your child.

Teenagers. Teenage cancer patients often face challenges specific to their age. Keep the following topics in mind to help your teenager cope:

- **Independence.** A cancer diagnosis may feel like a setback in your teenager's search for independence. Your teenager may need to rely on you more during treatment, which can lead to feelings of frustration. Respect your teenager's privacy and allow him or her the opportunities to do things alone when it is safe and appropriate to do so.
- **Fertility.** Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, needs to be done before treatment begins. Ask members of the healthcare team to help with this sensitive discussion. Additionally, some cancer treatments can interrupt the menstrual cycle. If your child is going through puberty and has already started menstruation, ask members of the healthcare team how the menstrual cycle may be affected and what to expect. Explain possible changes to your child.
- **Peers.** Teenagers often have active social lives. Not being able to participate in as many social activities as before the cancer diagnosis may be difficult for your teenager. Your teenager may also be very sensitive to changes in appearance such hair loss and weight changes. Encourage your teenager to stay in contact with friends as much as possible. Allow him or her to participate in activities that are medically safe.

- **Dating and Sexuality.** Your teenager’s social life may include dating. All teenagers need to know how to practice safe sex. Even if you think your teenager is not sexually active, make sure he or she understands the risks associated with having sex while receiving cancer treatment. Ask members of the healthcare team for help with this discussion. Teenagers may wish to talk to members of the healthcare team alone so that they feel comfortable sharing information and asking questions. They need to know that if they are sexually active, they must
 - Use some form of birth control. Pregnancy during cancer treatment can be unsafe for both the pregnant person and the baby.
 - Use condoms, or another barrier method, to protect against sexually transmitted diseases (STDs). Cancer treatment can compromise the immune system putting the person at higher risk for infection. Oral contraception (birth control pills) and implants (for example, an intrauterine device [IUD]) do not protect against STDs.
 - Ask the healthcare team if it is safe to have sex. There may be times that sex is unsafe for people undergoing cancer treatment. For example, if the patient is at risk for bleeding issues due to a low platelet count, he or she may need to refrain from sex until platelet numbers improve.
- **Tobacco, Drugs and Alcohol.** Talk to your teenager about tobacco, drug and alcohol use, even if you believe he or she does not use them. It may be dangerous to consume alcohol or do recreational drugs while taking certain medications or receiving certain cancer treatments. If your teenager uses any tobacco products, ask members of the healthcare team for smoking, “vaping” and/or tobacco cessation resources. Encourage your teenager to be honest with the healthcare team about any drug or alcohol use. Your teenager may wish to talk to the healthcare team about these sensitive topics privately.
- **Future Plans.** Your teenager may have already been making plans for the future, such as applying for college, internships or jobs. Cancer treatment may interrupt these plans. Talk to a social worker, child-life specialist or guidance counselor to find ways for your teenager to continue working toward his or her goals as treatment allows.



To learn more about considerations for teenage cancer patients, visit www.LLS.org/YoungAdults or visit www.LLS.org/booklets to view *Young Adults and Cancer*.

Wish Fulfillment. Many organizations at both the national and local level grant “wishes” for children who have critical illnesses. Wishes may include things such as a special vacation, a meeting with a favorite celebrity or the opportunity to try a new activity. Wish fulfillment provides children and their families with the opportunity to create lasting, joyful memories together during a difficult time.



For information on wish fulfillment, visit

- Make-a-Wish at www.wish.org
- Children’s Wish Foundation International at www.childrenswish.org

Visit www.LLS.org/wishes to view a list of organizations with programs that grant wishes. You can also ask members of your child’s healthcare team if your child may be eligible for any local programs that grant wishes.

Siblings. When a child is diagnosed with cancer, siblings may feel angry, anxious, lonely, sad, guilty, or even resentful of the new attention their sibling receives. You can help your children cope with a sibling’s diagnosis in some of the following ways:

- Be honest about the cancer diagnosis and treatment. Kids are very savvy and will come to their own conclusions if they think they are not being told the truth.
- Give information that is age appropriate, but don’t be overly concerned about giving too much information.
- If possible, introduce siblings to members of the healthcare team, who can help to give them medical information and reinforce that the siblings are special too.
- Give siblings the chance to talk about how the experience is affecting them.
- Be open and willing to answer questions about their brother or sister’s cancer and treatment.
- Reassure siblings that they cannot “catch” cancer from their brother or sister.
- Explain that no one did anything that caused the cancer.
- Warn siblings that their brother or sister may have less energy and/or lose his or her hair.
- Let siblings know about changes in routine in advance, when possible. Let siblings know where they will be staying (if not at home) and who will be staying with them. Whenever possible, give siblings the opportunity to make choices, such as whom they would like to care for them when parents are not available.
- Explain that other concerned family members and friends may ask them about their sibling’s diagnosis. Talk about appropriate responses.
- Remember that siblings still have their own problems, unrelated to their brother or sister’s cancer. Their problems are real and require your attention.
- Provide consistent, fair discipline to all your children, even though it may be more difficult right now.
- Allow older siblings to help with their younger brother or sister’s care in age-appropriate ways, such as reading a bedtime story.
- Make sure that all of your children know that you love them and are proud of them.

Siblings need to continue to go to school and participate in their usual activities, as much as possible. Ask friends, family members, other parents, and teachers for help. However, disruptions to routines are inevitable, and siblings may feel lost or overlooked. Arrange for regular time alone with each child.

Make the staff at your children’s schools aware that these children have a brother or sister at home who is being treated for cancer. Talk to the siblings’ teacher(s). Ask your hospital’s social worker or psychologist or your school psychologist whether your community offers any programs for siblings of children who have cancer.



SuperSibs, a program of Alex’s Lemonade Stand Foundation, provides programs and support for the siblings of children with cancer. Visit www.alexlemonade.org/supersibs to learn more.



LLS Pediatric Monthly and Weekly Calendar. Your entire family can use this free magnetic, dry erase calendar to keep up with each other’s busy schedules. Call an LLS Information Specialist at **(800) 955-4572**.

Parents. After a child is diagnosed with cancer, the parents of the child may feel a confusing mix of emotions—including shock and confusion, denial, fear, grief and sadness. These are all valid reactions. You and your co-parent may each react in different ways after the initial diagnosis. Every person is an individual with his or her own way of expressing emotions. There is no right way to feel or react. Respect each other’s coping styles to avoid blame and criticism.

Both you and your co-parent can be involved in your child's treatment. Discuss responsibilities and expectations early and discuss how your roles may change. Caring for a sick child is mentally and physically challenging and exhausting. By sharing responsibilities, you are allowing each other time to rest and recuperate. If only one parent takes on the bulk of the responsibilities related to the child's care, that parent may start to feel resentment toward the co-parent or feel that there is a widening gap in their relationship.

You and your co-parent may disagree at times about how to approach your child's treatment and care. Resolving these types of disagreements might be difficult, but it is important to do so in the interest of supporting your child. Resolving differences should not be thought of as a win-or-lose situation but as a collaborative means to provide the best care for your child. Do not discuss or argue about your child or issues related to his or her illness in front of him or her. Try to present a united front.

Maintain Your Relationship With Your Co-parent. Caring for a sick child can put a strain on your relationship or exacerbate preexisting issues. Make an effort to spend time alone together and to talk about topics other than your child. While that can be difficult, discussions about cancer can be all consuming. There was a time before the diagnosis when you likely discussed many different topics with your co-parent.

As treatment progresses, check in with your co-parent and ask how he or she is feeling. Always keep the lines of communication open. If you find yourself struggling with your relationship, reach out to members of the healthcare team for a referral to a family therapist.

Even when you are splitting responsibilities with your co-parent, caring for a sick child can be overwhelming. Both of you may be letting your own needs fall by the wayside. But, in order to be at your best for your child, you need to take care of yourselves too.

Parents often find that other parents who have a child with a cancer diagnosis are a source of support. Few people can understand what parents are going through as well as other parents who have a child with a similar diagnosis. Social workers at the treatment center may be able to introduce you to other parents or recommend a local support group for parents of children with cancer. Online support groups or chats are also an option.



The **Patti Robinson Kaufmann First Connection Program**: First Connection is a telephone support program that links you with a trained peer volunteer who has experienced a similar situation. Visit www.LLS.org/FirstConnection or contact an LLS Information Specialist at **(800) 955-4572** to learn more.

Separated or Divorced Parents. Separation or divorce is often difficult for families. The cancer diagnosis may put added strain on already difficult relationships. Nonetheless, it is very important to focus on what is best for your children. Set aside personal issues and work together so that both of you are making sure that your child is getting the best possible care. Consider the following suggestions; they can be helpful:

- Give the healthcare team a copy of any divorce decree, custody or visitation rights to add to your child's medical record.
- When possible, meet together with members of the healthcare team so that you can both ask questions and avoid confusion about appointments or treatment plans. Ask for two copies of all materials so that you each have one. To care for your child, you both need to be well informed on the diagnosis, treatment plan and potential side effects.
- Allow stepparents to be involved. If your child is spending time in both households, a stepparent may be caring for your child too. He or she will need to be knowledgeable about important medical information, such as how to give medications and which signs and/or symptoms require a trip to the emergency room.

- If your child spends time in two households, it may be helpful to keep a notebook that travels with your child from house to house. The notebook can contain notes about medication, side effects or other important information for the adult who is caring for the child at any given time.
- If the divorce or separation occurred recently, your children may need additional support to cope. Ask members of the healthcare team (for example, a social worker or child-life specialist) for guidance.

Coping Strategies for Parents (Listed by Emotion). Here are suggestions for managing some of the feelings, emotions and reactions that you and your co-parent may experience.

Shock and Confusion

The information you are given about your child's illness is often very complicated. When you learn that your child has cancer, you may initially block out other information about his or her illness.

- Ask members of the healthcare team to repeat information as needed.
- Ask members of the healthcare team for printed resources about your child's diagnosis and treatment.
- Some parents take notes or audio-record their meetings with their child's healthcare team so they can review what they were told and share it with other family members.
- Many families find it helpful to keep a notebook with the important information all in one place and to include the business cards of members of the healthcare team. It may also be helpful to create a calendar of your child's treatment schedule and medications.

Denial

Most parents would like to believe that their child's cancer diagnosis was a mistake. This is a normal reaction. However, parents who stay in a state of denial for too long may isolate both the child and other family members at a point when communication is very important.

- Before the child begins treatment, some parents seek a second opinion or research the doctor or treatment center.

Hope

Hope plays an important role in the ability to cope, particularly in trying times. Hope provides strength and motivation to continue forward.

- Talking with other parents whose children have had a similar diagnosis or gone through similar treatment and are now cured can sometimes be helpful. Knowing that other children with similar illnesses are cured can inspire hope that your child will be cured too.

Fear and Anxiety

You may experience many fears and worries related to how cancer treatment will impact your child and family. You may also worry about your ability to handle the situation.

- Some people find it helpful to talk about their fears and anxieties to close friends and family members, a support group or a healthcare professional.
 - Relatives and friends can often be a source of strength and understanding. However, some people mean well but are not helpful. They may deny the illness, offer homemade remedies or disapprove of your choices. Talk to members of the healthcare team for help coping with friends and relatives who are not supportive.
- Some people find it helpful to learn more about the disease and treatment. Ask members of the healthcare team for reliable resources and where to get information.

Anger

Don't be surprised if you feel angry at times. Parents of children who are seriously ill may experience anger at their child's diagnosis, wondering why this happened to their family. Their anger or frustration may be directed at their child's doctor, the healthcare system or the health insurance company. They may even feel angry with God for not protecting their child from the illness.

- Often there is no direct outlet for these angry feelings. As a result, emotions may be misdirected toward family members, co-workers or even complete strangers.
- Talking about angry feelings with trusted friends or relatives, a support group or a healthcare professional can help you work through these feelings.
- Some of the issues that cause anger or frustration may have a solution. Work with members of your child's healthcare team to change situations and/or resolve problems when possible.
- Physical activity and journaling are also good outlets for anger.

Guilt and Blame

Some parents may react to the stress of their child's cancer diagnosis by looking for someone or something to blame for the cancer. Almost all parents experience guilt—although perhaps for different reasons. You may worry that you passed on “bad” genes or did something wrong that caused the cancer. You may dwell on past regrets. You may blame yourself for not paying more attention to your child's signs and/or symptoms or seeing a doctor sooner. You may even have family members, friends or acquaintances who tell you that something you did caused your child's cancer.

- As hard as it is to accept, you may never know what caused your child's cancer. Remind yourself and your family members that no one is to blame.
- Talk to members of the healthcare team about these feelings in order to gain a better understanding of your child's illness.
- If friends or family members blame anyone for the cancer diagnosis, it is important to remember that they are not correct. Most likely they are trying to make some sense out of the situation, however wrong or inappropriate their reasoning.

Sadness and Loss

From the moment your child is diagnosed, you may feel a sense of loss. You may come to a realization that life for your child and family will never be quite the same. These feelings are normal. Over time, you will find ways to adapt and gradually develop a new sense of normalcy for you and your family.

- Allow yourself to feel sad when a sense of loss overwhelms you. However, if this emotion is consuming you or if you feel as though you are not functioning well, seek professional help. It is important to work through your own feelings so that you are able to help your child cope as well as manage other aspects of family life and work at the same time.

Doubts About Religious and Spiritual Beliefs

Your child's illness may seem unfair. The feeling of injustice can lead you to question your views on the meaning, purpose and value of life, or your spiritual beliefs and relationship with God. You may feel empty, cynical or discouraged.

- Exploring these feelings with the aid of a mental health professional or spiritual advisor is helpful for many parents.



The Courageous Parents Network (CPN) offers support and guidance for families as they care for a seriously ill child. Visit www.courageousparentsnetwork.org to learn more.

Extended Family Members and Friends. The support of family and friends will help you and your child throughout treatment. Friends and family members provide emotional and practical support. You can approach them and ask for help in some of the following ways:

- Choose one friend or a family member to become your “press secretary.” This person can update concerned friends and family members, as well as many other people who will likely reach out to offer support, on your behalf. This can be helpful because you may not have the time or energy to respond to everyone. Some families will share more information while other families will share less. How much you choose to share is up to you and your immediate family.
- Reminder: Be mindful when posting online. Even a private social media account may not be as private as it seems. If you choose not to share information about your child on social media, ask friends and family members to refrain from doing so too. Information shared online about your child now may still be visible in the future when your child is an adult.
- Ask for and accept help, even if you are not comfortable doing so at first. Most people want to help, even though they may need direction from you about how and when to help.
- Keep a list of tasks that others can help with, so when people ask how they can help, you have a specific answer. Many friends and relatives will want to help but need a little guidance on what kind of help will be most useful for you and your family.
- Keep a list of people who offer to help so you can call them when a need arises.
- Use a caregiver app to coordinate care. You can also use group email lists to provide updates and ask for help.

Your Child’s Friends. Cancer and cancer treatment can isolate a child. Your child may not be able to attend school, participate in recreational activities or see friends regularly during treatment. Finding ways for your child to stay in touch with friends of his or her own age is very important. Staying in touch with his or her friends provides a sense of normalcy for your child so that he or she can still have fun and feel connected.

Depending on the age of your child and your child’s friends, you may need to work with the friends’ parents to clear up any misunderstandings children have about your child’s cancer diagnosis. (For example, you cannot “catch” cancer, and no one did anything wrong to cause the cancer.) It may also be good to let your child’s friends know that he or she may have less energy or may look different (for example, hair loss from chemotherapy). You will want to stress that, despite these changes, your child is still the same person.

The following suggestions can help you to keep your child connected to his or her friends:

- Encourage your child to call, video chat, text or email friends. Your child can also write letters or draw pictures. If your child is a teenager, allow him or her to talk to friends privately.
- When your child is feeling well, arrange time to play and safe activities for your child and his or her friends.
 - Keep in mind that the friend’s parents may not realize the precautions you need to take for your child’s well-being. Ask the friend’s parent if his or her child is sick or has been sick recently before you set up a time to play.
 - If your child’s friend is sick, wait until the friend is feeling better before arranging a time to play. Your child’s immune system may be compromised from treatment, and he or she should not be exposed to illness.
 - Ask members of the healthcare team for further guidance on precautions you should take around your child spending time with other children.
- If approved by your child’s healthcare team, friends may be able to visit your child in the hospital if treatment requires your child to be inpatient. Plan these visits in advance so they do not interfere with treatment, procedures or nap times.
- If your child is staying in the hospital for treatment, ask if the hospital has a playroom. Your child can meet and play with other children who are also going through treatment.

Taking Care of Your Mental Health and the Mental Health of Others.

A childhood cancer diagnosis can be difficult for everyone involved—the patient, parents, siblings and other family members and friends. Feelings of anxiety and depression are common. When is it time to seek professional help? If these feelings start to interfere with daily activities, the person may need individual counseling from a medical professional.

Reach out to members of the healthcare team if you, your children or other family member is feeling overwhelmed by the following persistent feelings:

- Ongoing sadness or feelings of hopelessness
- Loss of interest or pleasure in most activities
- Major weight loss, weight gain or other changes in appearance
- Agitation or restlessness
- Fatigue or low energy levels
- Trouble sleeping or sleeping excessively
- Trouble focusing, remembering or making decisions
- Feeling worthless, guilty or helpless
- Thoughts of death or suicide

Additional signs to watch for in children include angry outbursts, nightmares or poor grades in school.

TIP:

For a referral to a mental health professional, reach out to the members of your child's healthcare team or call your insurance company for recommendations.

